

TESTIMONY
BEFORE THE DEPARTMENT OF PUBLIC HEALTH
REGARDING:

Revised Hospice Facility Regulations

Friday March 16, 2012

Dr. Mullen and Members of the Department of Public Health. I am **Carolyn Wolfe, MSW, Volunteer Director and social worker** for Regional Hospice and Home Care of Western Connecticut. I have been privileged to work with Regional Hospice and Home Care for nearly 5 years, and can attest from experience how much Western Connecticut could benefit from revised hospice facility regulations.

Recently, I worked with a woman named Mary. Mary was in her late 80s, had end stage lung disease, but was alert, oriented and incredibly self-directed in her plan of care. She had lived alone since she was widowed 20 years earlier, and was fiercely independent – something she prided herself on. Mary was terrified of what would happen to her when she was no longer able to live independently. She had strained relations with her adult children, and vowed she would never burden them with moving in with them or to have them in with her. Additionally, past negative experiences with live in help had her incredibly anxious about the idea of someone living in her home.

Mary and I talked for months about her developing plan of care. She talked openly about wishing there was a facility, nearby where her grandchildren could visit, where she could maintain her privacy in her own room, and where she was not reliant on her family to provide her care. She did not want an institutional setting like a nursing home; she needed home-like atmosphere, quality staff whom she trusted, and expert symptom management like she was already receiving at home.

In the end, Mary agreed to a private live in caregiver in her home. Unfortunately, the anxiety of this arrangement exacerbated her illness, and heightened the existing strain she and her adult children already had. Mary ended up going to the hospital in a crisis, and died, alone, contrary to all of her hopes and plans. Had there been an inpatient hospice facility in the greater Danbury area, Mary could have continued to direct her own plan of care with the Regional Hospice team whom she had grown to trust, and continued in a home-like environment where her family could visit her without taking on the direct caregiving role.

As a hospice worker, I often try to think about how I would manage should it be my mother, my father, my husband, or god forbid, myself in need of hospice services. In working with our younger patients, I hear the time and time again the struggles of these young families in trying to find the right balance of providing the direct hands-on care they want to for their loved ones, countered with the reality of also juggling employment (often necessary to keep their insurance benefits) and the needs of their children or other family members.

Would I want my sons, ages 5 and 7, to always associate our living room as the space that Mommy died? Would I want my husband to risk losing his job in having to stay home to care for me? Would I want my children to have to decide between the social networks that are critical to their development, and ultimately, to their bereavement, versus their ability to visit their mom regularly? Would I want them to visit me in a nursing home, where the other residents were twice my age and the facility staff unaccustomed to working with young families in this same manner? Clearly these would not be my choices – and sadly, these are not the choices that the young families we work with are comfortable making. The time has come that we allow families in Western Connecticut the chance to provide real options for how they will live the end of their lives – and hopefully in a place that is not that different from where they lived the rest of their lives.

Regional Hospice and Home Care of Western Connecticut has provided quality end of life care for nearly 30 years. It has built a reputation of professionalism, skill, empathy and humanity. Medicare Conditions of Participation guide our quality assurance standards (which we not only meet, we exceed), as do the staff themselves who are committed to providing the very best for each and every patient and family member. I strongly urge you to support the proposed revisions to the hospice facility regulations, including the following suggested wording: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**